

THE GROUP ON SCIENTIFIC RESEARCH INTO MYALGIC ENCEPHALOMYELITIS

(THE GIBSON PARLIAMENTARY INQUIRY)

CONCERNS ABOUT A COMMERCIAL CONFLICT OF INTEREST UNDERLYING THE DWP HANDBOOK ENTRY ON MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME

The information in this document is relevant to the Gibson Inquiry, specifically the continued ignoring by the Department of Work and Pensions (DWP) and its commercial advisers of the compelling scientific evidence that myalgic encephalomyelitis / chronic fatigue syndrome is not a primary psychiatric disorder. If eligibility for certain benefits becomes contingent upon the intended implementation of compulsory psychiatric “rehabilitation” regimes, in cases of authentic ME/CFS it is likely to result in serious relapse that may be life-long (and may in some cases even result in death)

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SUMMARY OF CONCERNS

This document sets out concerns about:

- (a) the commercial conflict of interest underlying the Department of Work and Pensions (DWP) Disability Handbook entry on myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) and
- (b) some aspects of the impending Incapacity Benefit reform.

It is of particular concern that:

- (i) as far as ME/CFS is concerned (and in general), the proposed psychiatric “rehabilitation” regimes ie. CBT (cognitive behavioural therapy) and GET (graded exercise therapy) that are to be imposed on UK claimants are poorly researched; they have already been shown to be of no lasting benefit, and they may be harmful: **in four surveys of a total of 3,074 ME/CFS patients, 77% of those who had tried CBT found that it either made no difference or made things worse, and of the 1,467 patients who had tried a graded exercise “rehabilitation” regime, 48% found it to be the most harmful intervention**
- (ii) financial compulsion will rob claimants of their right to give free consent to medical treatment
- (iii) the treatment regime of the patient’s own doctor will be overridden
- (iv) patients with no psychiatric history will be forced to attend mental health units
- (v) the psychiatrists advising the DWP who advocate this strategy have an undeclared financial conflict of interest: many are medical advisers to insurance companies

(vi) in addition, Professor Simon Wessely is involved with PRISMA, a multi-national healthcare company working with insurance companies to arrange “rehabilitation” programmes for those with ME/CFS. PRISMA claims to have developed a “unique treatment programme” for “hopeless” cases (in which it specifically includes ME/CFS). In the PRISMA Company Information, Wessely is listed as a Corporate Officer and as a member of the Supervisory Board; in order of seniority, he is higher than the Board of Management. Funding of these “rehabilitation” regimes by PRISMA has already begun in the UK. **It is of concern that Wessely is promoting and recommending a regime that is known to be harmful for those with authentic ME/CFS and that is provided by a company of whose Supervisory Board he is a member**

(vii) **in relation to ME/CFS, the unproven information upon which the DWP approach relies has been criticised in a Report commissioned by the New Zealand Ministry of Health**

(viii) recent briefings on reform of Incapacity Benefit indicate:

- that irrespective of their mental health status, claimants will be offered psychotherapy (Observer, 20th November 2005)

- that claimants who decline compulsory “rehabilitation” (because they may be physically too sick) will be refused benefit (Independent, 27th December 2005).

Senior Psychiatrists collude with Medical Insurers to classify ME/CFS as a psychiatric disorder

One of the goals of the UK Government – both Conservative and New Labour – has been and continues to be to achieve a significant reduction in the escalating cost of sickness and disability benefits by curtailing the number of those eligible to receive such benefits.

This is clearly necessary, but a key problem lies in determining who is genuinely sick and disabled (and therefore eligible for State disability benefits) and who -- under retirement age-- is capable of some form of employment.

Following the changes heralded in the 1993 Conservative Budget, in order to achieve the desired savings in disability benefits, the disability insurance company UNUMProvident was hired by the UK Department of Social Security (now the DWP) to train doctors to implement curtailment of eligibility for such benefits.

Since the involvement of UNUMProvident in the UK welfare system, so-called “medically unexplained” disorders with no definitive diagnostic test have become a prime target for the refusal and withdrawal of not only State sickness and disability benefits but also of medical insurance benefits: myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) has been specifically targeted by psychiatrists from the “Wessely School”, so named after its most notorious activist Professor Simon Wessely, who is on record as stating that ME does not exist.

Wessely School psychiatrists are heavily involved with UNUM and with the medical insurance industry in general; insurance companies in addition to UNUM with which they are known to be directly involved include Swiss Life, Canada Life, Norwich Union, Allied Dunbar, Sun Alliance, Skandia, Zurich Life, and Permanent Insurance, and as re-insurers, the massive Swiss Re (whose building in London has been dubbed the “gherkin”). For further information on the involvement of Wessely School psychiatrists with the insurance industry, see http://www.meactionuk.org.uk/Notes_on_the_Insurance_issue_in_ME.htm

It is widely believed that, because of their allegiance to their commercial paymasters, the Wessely School psychiatrists have been instrumental in blocking the necessary biomedical research into ME/CFS in the UK that would provide convincing evidence of biological markers that could result in a definitive test. These psychiatrists have certainly advised that in the UK no investigations should be performed on those with ME/CFS to confirm the diagnosis (they have specifically advised that such testing simply confirms ME/CFS patients’ erroneous belief that they are physically ill and is therefore counter-productive) and have advised that the condition is a primary psychiatric (behavioural) disorder. Both Professor Simon Wessely and his psychiatrist colleague Professor Michael Sharpe have consistently published and promoted their belief that it is wasteful of resources to investigate those with ME/CFS.

Wessely School psychiatrists have also been zealous in their efforts to remove ME/CFS from the World Health Organisation (WHO) formal classification as a neurological disorder and to get it re-classified as a “mental” disorder. If a definitive test existed, it would be impossible to refute the serious organic pathology that has been internationally demonstrated to underpin ME/CFS. Without such a definitive test, Wessely School psychiatrists are more likely to be successful in their aim of re-classifying ME/CFS as a “mental” disorder, with resultant profits for their paymasters, because “mental” disorders are excluded from insurance cover. On the other hand, if the correct

investigations were permitted to be carried out in the UK, and if the evidence of complex multi-system abnormalities was allowed to surface, then the psychiatrists' paymasters could not legitimately disregard such evidence and company profits would plummet. The insurance industry is determined that this must not happen: UNUM's "Chronic Fatigue Syndrome Management Plan" (dated 4th April 1995 and authored by Dr Carolyn L Jackson) makes this clear: **"UNUM stands to lose millions if we do not move quickly to address this increasing problem"**.

If those with ME/CFS who are incapable of work are deemed ineligible for State disability benefits, and if their medical insurance company refuses to pay out, what happens to them? In 21st century Britain, unless those with ME/CFS accept that they have a mental / behavioural disorder, with consequent loss of higher-rate State benefits for which they ought to qualify, they are simply abandoned, because the UK DWP has effectively sanctioned the withdrawal of support from those who most need it.

For examples of the scientific evidence that Wessely School psychiatrists continue to ignore and suppress, see our Submission of 12th December 2005 to the Gibson Inquiry ("Illustrations of Clinical Observations and International Research Findings from 1955 to 2005 that demonstrate the organic aetiology of ME/CFS").

For substantiation that this scientific evidence has been deliberately and consistently ignored by UK Government Departments, and of the involvement of the Wessely School in the suppression of this evidence, see our Submission of 7th November 2005 to the Gibson Inquiry ("Chronological list of documents relevant to the Inquiry authored by Professor Malcolm Hooper, Eileen Marshall and Margaret Williams").

Because of the far-reaching influence of the Wessely School, the existing body of scientific evidence demonstrating that ME/CFS is a genuine medical disorder (not a behavioural disorder as proclaimed by them) has been comprehensively ignored by Government departments for over a decade, and the unproven beliefs of these psychiatrists have gained unwarranted dominance.

This is despite the fact that the same Government bodies are on official record on many occasions as accepting that ME/CFS is an organic disorder.

Government Departments recognise ME/CFS as an organic disorder

- ME was recognised as a physical disorder on 27th November 1987 (Hansard: HC353)

- This was confirmed by James Mowbray, Professor of Immunopathology at St Mary's Medical School, London, in a letter distributed by the ME Association: **"In November 1987 ME was recognised as an organic disorder by the Department of Health"**

- The ME Sufferers Bill was presented to the House of Commons by Jimmy Hood MP on 23rd February 1988 and passed its first reading unopposed. The second reading was on 15th April 1988. The Bill asked for an annual report to Parliament: **"It shall be the duty of the Secretary of State (for Health) in every year to lay before each House of Parliament a report on the progress that has been made in investigating the causes, effects, incidence and treatment of the illness known as ME"**. Hansard for 23rd February 1988 at columns HC167-168 records: **"There is no doubt that ME is an organic disorder. The sufferers are denied proper recognition, misdiagnosed, vilified, ridiculed and driven to great depths of despair"**

- Although not a Government body, in 1988 the British Medical Association formally made clear its position about ME/CFS and confirmed that it was sympathetic to sufferers

- In 1989, journalist Caroline Richmond pointed out: **"Myalgic encephalomyelitis is the first and indeed the only disease legally recognised in Britain, thanks to a private member's Bill passed in 1988"** (BMJ 1989:298:1295-1296)

- On 5th June 1991 the (then) UK Attendance Allowance Board Secretariat at The Adelphi, 1-11 John Adam Street, London WC2N 6HT (which worked in liaison with the Department of Health) sent a letter signed on behalf of Mrs CV Dowse confirming that: **"Recent research indicates that ME must be a physical reaction to some type of virus infection"**

- In a letter dated 13th March 1992 to James Pawsey MP (ref: POH (3) 2484/200), in his capacity as Parliamentary Under Secretary of State for Health, Stephen Dorrell MP set out the official view of the Department of Health on ME: referring to the Disability Handbook produced by the Disability Living Allowance Advisory Board, Mr Dorrell stated: **"The Handbook recognises that in some persons with ME there is evidence of persisting viral infections in muscles, with some evidence of muscle damage. Hence, a physical cause for ME is recognised"**

- On 16th August 1992, the same Parliamentary Under Secretary of State for Health, Stephen Dorrell MP, publicly confirmed that: **“ME is established as a medical condition”**
- On 18th January 1996, the official view of the Department of Health was set out in a letter to an MP (ref: POH (6) 4139/192) in terms: **“The Government accepts that ME/CFS can follow a post-viral infection”**. This letter was signed by Baroness (Julia) Cumberlege in her capacity as Parliamentary Under Secretary of State for Health
- In the British Library Current Awareness Topics Update for March 2000 is listed (on page 6) the following: **Social Security Ruling, SSR 99-2p; titles II and XVI; evaluating cases involving chronic fatigue syndrome (CFS). Fed Regist 1999 Apr 30;64(83);23380-4: “In accordance with 20 CFR 402.35(b)(1), the Commissioner of Social Security gives notice of Social Security Ruling SSR 99-2p. This Ruling clarifies disability policy for the evaluation and adjudication of disability claims involving Chronic Fatigue Syndrome (ME/CFS). This Ruling explains that, when it is accompanied by appropriate medical signs or laboratory findings, ME/CFS is a medically determinable impairment that can be the basis for a finding of “disability”. This Ruling ensures that all adjudicators will use the same policies and procedures in evaluating disability claims involving ME/CFS, and provides a consolidated statement of these policies and procedures”**
- This was reported in the Disability Rights Bulletin, Summer 2000 in the following terms: **“In assessing DLA higher rate mobility component for people with ME, recent guidance advises decision makers to assume in the vast majority of cases that the claimant has a physical disablement. The Commissioner, in CDLA/2822/99, held that an award of the higher rate mobility component can be made on the basis of the physical element of the condition. Guidance (DMG Memo Vol. 10-3/00) advises decision makers that, in the vast majority of claims, if a doctor says the claimant has ME or CFS then that can be taken as an opinion that they have a physical disablement”**
- A letter dated 30th May 2001 from the Department of Health and signed by Linda Percival of the Health Services Directorate (ref: TO 2001 / 15353) states: **“To improve services for people with long-term illnesses, the Government recently announced a National Services Framework (NSF). The NSF will have a particular focus on the needs of people with neurological disease. It is very likely that chronic conditions such as ME/CFS will be included”**.

The Arrival of UNUMProvident into the UK Benefits System

Such official recognition notwithstanding, after the commercial interests of the disability insurance industry and its Wessely School 'medical advisers' became instrumental in the UK benefits system, the situation for those with ME/CFS took a serious turn for the worse.

Dr Peter Dewis from the DWP / DLA Advisory Board (who, together with Professor Mansel Aylward authored the Disability Handbook and is now Chief Medical Officer at UNUMProvident – see below) confirmed that before Attendance Allowance became the Disabled Living Allowance (DLA), decisions on eligibility for State sickness and disability benefits were made by doctors (hence the “Handbook for Delegated Medical Practitioners”), but since the advent of DLA, such decisions are now made by non-medical personnel, and the “Disability Handbook” is a guide for these non-medical decision-makers.

For a company that was hired to work within a UK Department of State, UNUMProvident has an interesting track record and a reputation that continues to date:

- Founded in Portland, Maine, USA in 1848, UNUMProvident is a massive multi-national company that specialises in disability and illness insurance and it has a virtual monopoly in this market (for example, HSBC Life is part of UNUM)
- After the 1993 Budget, Peter Lilley, then Conservative Social Services Secretary, hired the Vice President of UNUM private insurance company to help in his bid to save £2 billion per year by slashing the benefits for disabled people
- As reported in Private Eye (“Doctors On Call”; issue 874, 16th June 1995, page 26), to whom grateful acknowledgement is made, UNUM’s Chairman, Ward E Graffam, enthused about “exciting developments” in Britain: **“The impending changes to the State ill-health benefits system will create unique sales opportunities across the entire disability market and we will be launching a concerted effort to harness the potential in these”**

- As Private Eye noted, with so much less government money going to sick and disabled people, the opportunities for private disability insurers were enormous
- Crucial to the new UK disability rules were tougher medical tests. To this end, new tests were introduced that were fundamental to the savings Peter Lilley hoped for. To implement the tougher new tests, Lilley's Department set up a "medical evaluation group" for which they recruited a new corps of doctors; as Private Eye noted, the most famous member of that group was Dr John Le Cascio (Vice President of the UNUM Corporation), who was seconded to the company's British arm based in Dorking, Surrey
- Le Cascio was invited by Lilley's Department to help in the extensive training of the new "medical evaluation group"
- No press release was issued about Dr Le Cascio's appointment. No-one told taxpayers that the UK Government was shelling out for Dr Le Cascio's services at a cost of £40,000
- The Department of Social Security, as it then was, stressed that "Doctors do not decide the benefit – that is done by adjudication officers", but as Private Eye noted, the officers would be making decisions based on medical opinion provided by doctors trained by UNUM (and UNUM's remit was to reduce those eligible for UK State disability benefit)
- **Private Eye asked Dr Le Cascio if he agreed that there was an obvious conflict of interest in his position as monitor of tests for a benefit, the cutting of which was being exploited to the full by his company; his reply was not unexpected: "To me, there is no sort of conflict, and I assume that those in the Department feel comfortable with my contribution"**
- **It was the same Dr Le Cascio who, together with Professor Simon Wessely and his psychiatrist colleague Professor Michael Sharpe, spoke at a Symposium entitled "Occupational Health Issues for Employers" held at the London Business School on 17th May 1995, at which attendees were informed that ME/CFS has been called "the malingerer's excuse"**
- **UNUMProvident is notorious for its view that ME/CFS is 'Neurosis under a new banner'. This is set out in the company's "Chronic Fatigue Syndrome Management Plan" referred to above, and the same document also states: "Physicians must work with UNUM rehabilitation services in an effort to return the patient / claimant back to maximum functionality **with or without symptoms**"**

- Ten years after being invited to streamline the UK disability benefit system, UNUMProvident sponsored the Labour Party Conference in 2003

- In August 2004 UNUMProvident issued a Press Release reporting a striking 4000% increase in claims for syndromes that are primarily symptom-based, including ME/CFS

- In 2004 UNUMProvident funded the UNUMProvident Centre for Psychosocial and Disability Research at Cardiff University, claimed to be the first of its kind to extend understanding of the “psychosocial and cultural factors” and the “beliefs and attitudes” that the Wessely School psychiatrists (and the disability insurance industry) believe modify behaviour in relation to disability. UNUMProvident claimed about its new Centre: “This will bring about benefits to employers, insurers and to society as a whole”

- In October 2004, Professor Mansel Aylward CB took up the first Chair in Psychosocial and Disability Research at Cardiff University, where he is also Director of the new UNUMProvident Research Centre for Psychosocial and Disability Research at Cardiff University (which Aylward has developed with a £1.6 million grant from UNUMProvident). Aylward was previously Chief Medical Adviser, Medical Director and Chief Scientist at the UK Department of Work and Pensions. He was also Chief Medical Adviser and Head of Medical Professions at the Veterans Agency, Ministry of Defence. During his time at the DWP, Aylward was well-known for his support of the Wessely School and for his opposition to State disability benefits being paid to ME/CFS claimants. During his tenure at the DWP, Aylward is on published record as indicating his own and his Department’s disapproval of the UK Chief Medical Officer’s 2002 Report on “CFS/ME” (the Chief Medical Officer, Professor Sir Liam Donaldson, is on record on 11th January 2002 as stating that CFS/ME should be classified alongside multiple sclerosis and motor neurone disease) and of preferring the opinions of the psychiatrists who resigned from its Working Group. There would seem to be *prima facie* evidence that during his time at the DWP, Aylward was a veritable Trojan horse into the DWP for both the Wessely School and UNUM. There would also appear to have been a clear financial conflict of interest and possible breach of Civil Service protocol, in that a senior Civil Servant such as Aylward could not have been unaware while he was in post at the DWP that UNUMProvident was already financing his next employment which would allow him to indulge in his existing conviction that syndromes such as ME/CFS are affected by “cultural” factors and are “behavioural” in nature. It is also a matter of concern that a senior Civil Servant accepted sponsorship from a company with UNUM’s track record

- Evidence exists to show that the insurers reject medical reports from ME/CFS experts and will accept only reports supplied by their own company medical advisers (ie. Wessely School psychiatrists)

· Of concern is that Wessely School psychiatrists usually fail to declare their competing private sector interests in British medical journals or, for example, on the Chief Medical Officer's Working Group, although it is noted that Wessely did so on one occasion in an American medical journal (JAMA).

Parliamentary Concerns about UNUMProvident in relation to ME/CFS

Members of Parliament are on record as being gravely concerned about the difficulties their constituents with ME/CFS face with UNUM, as recorded in the House of Commons debate chaired by Sir Alan Haselhurst on 21st December 1999 (see Hansard 147WH – 166WH). The concerns voiced were that:

1. **“So extreme are the practices of that company that a UNUM support group has been set up for people in a similar situation. It has 250 members and estimates that 4,000 people are in similar situations throughout the country”**

2. **“It is not only people in the United Kingdom who are suffering such problems. There is documented evidence from throughout the United States, where UNUM is the largest company that provides such insurance cover. There is evidence of such cases from Australia and Canada, and I have no doubt that people in other countries also suffer as a result of the sharp practices of UNUM and similar companies”**

3. **“All claimants are sent to a psychiatrist, whose diagnosis is subject to questionable decisions”**

4. **“It shows that insurance companies are prejudging the causes of and the treatments for ME before consensus has been reached in the medical profession”**

5. **“If they have been treated by an ME specialist who favours another method of diagnosis and treatment, they may find that their disability insurance payments cease”**

6. **“Several patients were forced to attend named psychiatric clinics and to receive cognitive therapy, graded exercise and psychoactive drugs. They were told that if they did not they would lose their pension rights”**

7. **“The ombudsman recently turned down Mr. Little's appeal on the ground that ME might not exist as an illness and that, if it did exist, it was of a psychological nature and Mr. Little was therefore in need of psychotherapy”**

8. **“Swiss Life forced her to see a psychiatrist with known views on the causation of ME by threatening to stop her payments; but she has been refused sight of the psychiatrist's report”**

9. **“Mrs Dale believes that most insurance companies regard ME as a psychiatric illness and think that people suffering from it should undergo cognitive behavioural therapy. The waiting list is up to a year and only a few cognitive behaviour therapy treatment centres are aware of ME. Worst of all, many insurance companies cut off benefits while people are awaiting treatment, creating financial hardship for ME sufferers and their families”**

10. **“I am alarmed to hear from hon. Members that insurance companies can insist on a treatment set out by their medical assessors, who are doctors employed by them”**

11. **“That illustrates what a nonsense all this is. People have a right to choose medical advisers and those who treat their illness. They cannot be forced to accept a certain treatment, whether cardiac surgery or cognitive psychotherapy. If people are ill, they are ill. Clearly, an insurance company has the right to seek medical advice about the validity of a diagnosis. It cannot, however, insist on treatment being carried out by its own clinicians or others”**

12. **“I was interested to learn that UNUM has advised the Benefits Agency's medical division. That explains some of the unimpressive decisions made by doctors on behalf of the Benefits Agency”.**

At the end of 2005, MPs' postbags continue to bulge with horror stories from their constituents about the same issue.

UNUMProvident subjected to punitive fines in numerous legal actions

- UNUMProvident has been found guilty in numerous high profile legal cases of unwarranted delays in the processing of claims and of wrongful denial of claims, resulting in awards of punitive damages against the company for its improper refusal to pay legitimate claims
- In a claim against UNUM brought by Dr Joanne Ceimo (who was unable to work as a cardiologist following a neck injury), UNUM faced \$84.5 million damages for “mistreating an injured policy holder”, including \$79 million in punitive damages. Dr Ceimo’s lawyers said that evidence from previous policyholder cases against UNUM helped pave the way for this verdict
- In another case against UNUM, Judge O’Malley Taylor criticised UNUM, saying: “There is clear and convincing evidence that (UNUM’s) bad faith was part of a conscious course of conduct firmly grounded in established company policy”
- A federal lawsuit filed in New York sought to represent tens of thousands more UNUM policyholders as part of a class action against the company, and in another case, the State of Georgia recently fined UNUM \$1 million over its claims handling practices
- UNUM’s own former medical director, Dr Patrick Fergal McSharry, has filed a lawsuit against the company, claiming that the company’s “primary purpose and policy” was to deny disability claims
- He also stated that company medical advisers were encouraged to use language in their reports that would support claim denials, and that if too many medical opinions favoured the policyholder, the doctors would be reprimanded or sacked
- Another UNUM policyholder, Accident and Emergency physician Dr Judy Morris, discovered that her claim had been denied due to the input of Professor Michael Sharpe’s “evidence” that ME/CFS is a psychiatric disorder (upon which UNUM apparently relies to support its stance that psychological rehabilitation regimes will cure ME/CFS, which is apparently the basis upon which UNUM relies to deny ME/CFS disability claims). When she contacted him, Dr Morris received an

email from Sharpe telling her that UNUM's employees were not the "monsters" she was making them out to be

- In November 2004 The New York State Insurance Department reached a settlement with UNUM Provident: the company agreed to a fine of \$15,000,000. On pages 12-15 of the February 2005 issue of "ME Essential", the magazine of the UK ME Association, the Association's Medical Adviser wrote about this case: "UNUMProvident Corporation has agreed to re-assess more than 200,000 disability claims it originally denied since 1997 (in order) to settle (an) investigation (that) included a \$15 million fine (for) unfairly evaluating the medical conditions of people making a disability claim (and for) relying too heavily on in-house medical staff to deny, terminate or reduce insurance benefits"

- The same article noted that in the UK, "when a dispute arises over eligibility, doctors called in to conduct disability assessments often have a close and regular financial association with the insurance industry. It is not acceptable for the insurer to interfere with or take control over medical management. There are certain types of medical experts who are very happy to do insurance work. Such doctors tend to support the view that many ME sufferers are malingerers. Needless to say, certain doctors have been extensively supported by the insurers and the names of these psychiatrists appear repeatedly"

- On 4th April 2005, respected international expert in ME/CFS Professor Charles Lapp from Duke University, Charlotte, North Carolina, chaired a meeting of the ME/CFS Advisory Committee on Disability Issues; tactics used by the insurance industry to deny claims were identified as:

- (i) relentless harassment of claimants; (ii) threats to claimants; (iii) covert surveillance of claimants; (iv) unlawful interference with the mail of claimants; (v) denial of legitimate claims --- not paying claims, regardless of merit, no matter what proof is provided; (vi) claimants forced into legal action when they are too ill to launch an appeal; (vii) delays lasting years in processing legitimate claims; (viii) arbitrary termination of claims; (ix) habitually ignoring pertinent, objective medical evidence that supports a claim; (x) claimants subjected to years of systematic slander, victimisation, ridicule, harassment and acts of terror; (xi) changing the diagnosis to mental illness under duress to allow insurers to terminate benefits; (xii) employing company doctors who have no appropriate knowledge or clinical experience of ME/CFS

- In one High Court action in the UK, UNUM employed private investigators over a period of eleven years but still had no evidence to offer, which the Judge thought remarkable

- In September 2005, the Book Review Section of the New York Times (NYT) featured a book that had just been published about UNUM's disability claims abuses ("Insult to Injury: Insurance, Fraud,

and the Big Business of Bad Faith” by attorney Ray Bourhis; Berrett-Koehler Publishers, Inc., SF). The item in the NYT Book Review stated: “Joan Hangarter trusted UNUMProvident --- until she became disabled and consequently found herself and her children broke and homeless after UNUMProvident terminated her claim, cancelled her policy and stopped paying her benefits she was rightfully owed. (She) won a landmark \$7.7 million jury verdict against UNUMProvident. Bourhis uses (this) story and the stories of others to expose how insurance companies get away with denying valid claims, terminating benefits, and destroying people’s lives”

- Because it cannot be free from corporate interests, UNUM’s official association with UK Government bodies inevitably places its corporate interests above the welfare of those in the UK claiming sickness and disability benefits (because it has direct financial interest in securing cutbacks in State sickness and disability benefits)

- Disability insurance policy requirements increasingly imply the requirement for a claimant to participate in a “physical rehabilitation” regime for the duration of a claim, and that disability benefits may be terminated if a claimant refuses to take part in such (Wessely School) “rehabilitation” regimes.

Psychiatrists – who have undeclared private sector interests – continually attempt to influence the entry in the DWP Disability Handbook in relation to ME/CFS

The following pages briefly consider the long-term persecution of those with ME/CFS in the UK by the DWP and the disability insurance industry (and their Wessely School psychiatrist advisers) in relation to sufferers’ disability claims.

Despite the evidence that UK Government Departments accepted ME/CFS as a legitimate organic disorder in 1987, the DSS (now the DWP) has remained intransigent in its attitude to claimants with ME/CFS.

Such persecution has occurred because of the expedient suppressing, dismissing and ignoring of the available scientific evidence by this group of psychiatrists who have a vested interest in preventing the acceptance of ME/CFS as an organic disorder and therefore widely promote it as a behavioural disorder; they have been able to do this because they were / are acting as medical advisers to the disability insurance industry, which in turn was acting within the machinery of the State.

Such a position of influence afforded Wessely School psychiatrists not only the opportunity to suppress the international scientific evidence on ME/CFS in the UK, but it also afforded them the opportunity to mislead Ministers of State.

For example, in 2003 Dr Stephen Ladyman MP, Parliamentary Under Secretary of State for Community Care, wrote to an MP that the WHO had now classified ME/CFS as a mental health disorder: he failed to distinguish between the WHO itself and the Institute of Psychiatry that acts as a WHO Collaborating Centre. It was in fact the Institute of Psychiatry, where Simon Wessely works, that had reclassified ME/CFS as a mental disorder in its "Guide to Mental Health in Primary Care". Dr Ladyman in turn misled MPs, who in turn gave wrong information about ME/CFS to their constituents.

When it was pointed out by the ME community that this information was incorrect, Dr Ladyman seems to have been advised of the stance that was then, of necessity, hurriedly taken by the Wessely School, writing on 29th August 2003 that: "The current version (of the International Classification of Diseases) classifies CFS in two places; as Neurasthenia / Fatigue Syndrome in the mental health chapter (F48.0) and as Post Viral Fatigue Syndrome / Benign Myalgic Encephalomyelitis in the neurology chapter (G93.3). Close examination shows that the WHO has essentially put the same condition in both places".

Whilst this was certainly the view that the Wessely School psychiatrists promoted, it also was untrue and therefore misleading. The WHO Headquarters in Geneva refuted it, confirming in writing that: "According to the taxonomic principles governing the Tenth Revision of the World Health Organisation's International Statistical Classification of Diseases (ICD-10) **it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive**".

Despite the best efforts and pervading influence of the Wessely School, the UK Department of Health was once again forced to concede that the correct classification for ME/CFS is neurological: by letter dated 11th February 2004, the Health Minister, Lord Warner, wrote to the Countess of Mar: "**During this important debate on 22nd January (2004) you raised points about the WHO classification of CFS/ME. Since the debate, the WHO, the WHO Collaborating Centre and the Department of Health have now agreed a position on the classification of CFS/ME. The UK accepts the ICD-10. In the debate I said that 'ICD-10 classifies CFS in two places: as neurasthenia in the mental health chapter, F48.0; and as myalgic encephalomyelitis in the neurology chapter, G93.3'. The Department accepts that it might have been clearer to say that chronic fatigue syndrome is indexed to the neurology chapter and fatigue states to the mental health chapter**".

This would seem unequivocal enough for use by the DWP, but the Wessely School psychiatrists and their paymasters in the insurance industry do not agree.

Since the advent of UNUM into the UK benefits system in 1993, the entries that purport to describe ME/CFS in the Disability Handbook and related correspondence make harrowing reading.

Examples include the following:

1994

Despite the undeniable fact that ME has been included as a distinct (neurological) entity by the WHO in the ICD since 1969, Aylward's Department produced the following entry which, in contemptuous defiance of the scientific evidence of the organic nature of ME/CFS, is the unmistakable view of the Wessely School psychiatrists:

"The Disability Living Allowance Advisory Board (DLAAB) has consulted widely and has concluded that there is no firm evidence to-date to identify ME as a distinct entity. In addition the board has concluded that the case for (ME/CFS) being a physical disease is, at present, unproven. The general consensus of informed opinion is that treatment should be by graded exercise and rehabilitation. In some cases, antidepressant drugs may be helpful. The majority of people with fatigue syndromes recover within a few weeks or months".

Following this entry in the Handbook, on 14th October 1994 the Chief Executive of the Benefits Agency (Michael Bichard) wrote to David Heathcoat-Amory MP (ref: DB 213189) with even more disturbing news about the DLA: " Where the Secretary of State considers that there are grounds for a review of a particular case, **whether there was an award for life or not**, he may request this. In Mrs X's case a review was undertaken and a further medical report was requested (and) the adjudicating officer decided to revoke the award of DLA. As you know, Mrs X is diagnosed as having ME which is a controversial condition on which a number of doctors hold strong but differing opinions".

The March 1995 issue of the ME Association's magazine reported on page 8 the acute dismay at what it called the "appalling" entry in the 1994 DLA Handbook: "Having made good progress during 1993, we were shown a draft which closely followed our suggestions. However, in early 1994, we were asked to provide speakers (for) the Board (*one of whom was Dr Charles Shepherd*) in order to give them another point of view from that presented by two speakers who had been called to the Board after we had seen the new draft. This we did. (*The two speakers called by the Board are known to have been Dr Simon Wessely and Professor PK Thomas, known for their published view that the muscle weakness suffered by those with ME/CFS is "simulated"*). The new entry is worse than the last".

1995

On 4th April 1995, Dr Adrian Furniss, a Medical Officer from BAMS (Benefits Agency Medical Services) wrote the following about ME/CFS on a BAMS Advice Sheet: **"Most lay press articles favour the existence of a physical disease. The weight of medical opinion regards this as a psychosomatic disorder (and) the majority of these cases are somatisers. For national guidance, the DLAAB does not accept a case for physical problems has been proven. Gradually increasing exercise programmes would likely have a significant impact on fitness within weeks. As regards treatment of a somatisation or behavioural disorder, strong encouragement of more normal behaviour is important, with avoidance of anything that rewards, acknowledges or enables mal-adaption (*sic*). ME is a fashionable label and not pathology in its own right. Many thousands of pounds worth of tests prove nothing. The label ME is a rag bag representing no proven pathology. Encouraging illness behaviour is likely to prolong and aggravate this type of behaviour. Behavioural treatment would be as important if not more important than any antidepressant medication. The DLA Advisory Board has expressed a strong opinion as regards such labels after considerable consultation with many experts"**.

1998

Following the opening two paragraphs of the Queen's Speech delivered to both Houses of Parliament on 24th November 1998 (which included: "My Government will continue in their drive to modernise the welfare state upon the principle of work for those who can and security for those who cannot"), the subsequent issue of the ME Association's Magazine reported (on page 6) the following: **"Many of our members are most certainly unable to work and the apparent treatment some of them receive from the Benefits Agency makes them feel anything but secure. There appear to be major problems in the way the agency is administering some of the Social Security**

and Disablement Benefit claims. Adjudication Officers appear to be unable to effectively assess the care and mobility needs of (ME/CFS) claimants through bias. Adjudication Officers appear to be failing to give full credence to *all* evidence submitted (and) failing to seek additional medical evidence apart from that provided by BAMS. Appeals can take up to a year to be heard”.

2000

The Incapacity Benefit Handbook (Revised) entry for (ME)CFS stated: **“A mental health assessment will almost always be appropriate. You will find it quicker and easier in the long run to approach the assessment on the basis that the mental health section will need to be completed. If you do not complete the mental health assessment you must fully explain your reasons for not doing so. The approved doctor will need to be aware that there is a developing consensus on the medical management of (ME)CFS which emphasises gradually increasing activity together with cognitive behavioural therapy. Indicators of a good prognosis (include) a management regime which concentrates on lifestyle modification. Indicators of a poor prognosis (include) the presence of multiple symptoms especially those suggesting somatisation”.**

2003

(With grateful acknowledgement to Steve Donnison, www.benefitsandwork.co.uk)

In December 2003 Professor Mansel Aylward CB, Chief Medical Adviser to the DWP’s Corporate Medical Group, gave evidence to the Public Accounts Committee’s enquiry into progress in improving the medical assessment of incapacity and disability benefits. The Committee was very concerned that 51% of appeals against Incapacity Benefit and DLA decisions were being won by claimants. There was clear scepticism by the Committee about the skills of the privatised doctors (ie. those working for the DWP). According to the evidence given at this hearing, these doctors receive between £50 - £70 per medical, which would allow them to earn in excess of £100,000 per year. Professor Aylward leapt to the defence of the (DWP) private doctors: his evidence was that in his professional opinion, the privatised (DWP) doctors who refused claims had got it right and the appeal tribunals had got it wrong, as the privatised (DWP) doctors were better trained. When asked why this alleged problem of poor training of appeal tribunal doctors apparently persisted, Aylward responded: “I am working very closely with the President of the Appeals Service to ensure that the difference is remedied”. By this, Aylward was saying that in his opinion there was a problem with the training and validation of Appeals Service doctors, and also that it was accepted that this was the

case because Judge Harris, President of the Appeals Service doctors, was working with him to remedy the problem. Alan Williams MP then asked Aylward if he had fed his concerns on this issue into the system, and at what level had he fed his concerns into the system. Aylward replied: "I fed it in at the highest level. I fed it in at the highest level in the Appeals Service. I have made my colleagues in DWP aware of it".

At Benefits and Work, Steve Donnison was very concerned at the possibility that someone (ie. Aylward) appeared to be in a position to influence the President of the Appeals Service and possibly persuade him that the Appeals Service doctors, like DWP doctors, should be trained by a privatised company in order to reduce the number of claimants winning appeals. Donnison therefore sought clarification from Aylward and under the Freedom of Information Act asked to see copies of any communications between him and Judge Harris about Aylward's concerns over the poor quality of the Appeals Service doctors. Aylward's reply was curious: "I have not personally written to Judge Harris or anyone else within or connected to the Appeals Service". Mindful of Aylward's evidence to the Public Accounts Committee, Donnison again asked Aylward for information about the work he had undertaken with Judge Harris and any documents relating to it. Given Aylward's evidence to the Committee that he was working very closely with Judge Harris and that he had fed his concerns into the system at the highest level, Aylward's written reply was astonishing: "I have no documents or communications. The limited feedback I have given to the Appeals Service has been given verbally".

The apparent disparity in Aylward's evidence is not an insignificant matter because his evidence to the Committee appeared to be the undermining of MPs' faith in the judgments of the Appeals Service doctors (who allegedly allowed undeserving claimants, including those with ME/CFS, to receive State benefits).

Whether or not the Chief Medical Advisor at the DWP misled a Commons Committee is a grave matter.

Of further importance is the fact that not long after the Committee hearing, the bidding process started for a contract for £500 million of taxpayers' money to carry out DLA and Incapacity Benefit assessments for a further seven years and the opinion of bodies like the Public Accounts Committee would have to be taken into account in deciding who should get the contract.

At the same time, UNUMProvident was setting up its new Centre for Psychosocial and Disability Research at Cardiff ready for Aylward to step into when he left the DWP, where he could continue his work of trying to persuade GPs to stop signing so many people off sick with conditions like ME/CFS and could concentrate on bringing not only increased wealth to UNUMProvident, but also big savings for the DWP.

2004

Chapter 16 (“The Chronic Fatigue Syndrome”) of the Disability Handbook states: **“Physical disability may be influenced by the psychological state of the person. In those with the severest disability there is an increased likelihood of treatable psychological disorders and mental health problems”.**

In the 2004 “Fitness for Work” Handbook (the definitive text on fitness for work assessment), **chronic fatigue syndrome (ME) appears in the chapter on ‘Psychiatric Disorders’.**

On 28th June 2004 the Minister for the Disabled, Maria Eagle MP (part of the team running the DWP) was asked by ME Association Trustee Mrs Angela Flack why unfair obstacles are placed on people with ME/CFS to prove their illness beyond doubt, mostly with little support from GPs, social workers and occupational therapists, who themselves have little knowledge of the condition. Maria Eagle then invited the ME Association to give her proof that the DWP’s Disability Handbook did not accurately reflect the severe disabling effects of ME.

Despite this invitation, it seems that the evidence provided has been consistently ignored and that the psychiatric bias continues to dominate DWP thinking about ME/CFS.

The ME Association magazine “ME Essential” (October 2004, page 2) reported that new DWP proposals would force those who claim Incapacity Benefit to have a medical check-up every three months and to undergo “continuous reassessment”. If claimants turn down what the DWP deemed to be “suitable” work, their benefits could be axed altogether. An ME Association member from Lincoln, Mrs Mary Daley, wrote: “I claim the benefit and find the annual review stressful enough. The new proposals will mean a continuous review and a medical every three months. These changes amount to harassment of very ill people. ME sufferers have a hard enough time claiming their rightful benefits, and then to be physically and mentally tortured in this way is a terrible prospect”.

2005

On 10th June 2005, new draft Guidelines on the eligibility of those with ME/CFS for State disability benefits were handed out at the close of a meeting held at the DWP. The new draft revision had been drawn up by the “CFS Group” at the DWP to replace the existing entry in their Decision-Makers’ Handbook; the draft Guidelines were handed out on the basis that their circulation was to be restricted to those at the meeting.

However, this draft version has been obtained and is now available to members of the public through the good auspices of Steve Donnison, webmaster at www.benefitsandwork.co.uk, to whom grateful acknowledgement is made. Enquiries should be directed to info@benefitsandwork.co.uk .

It has been ascertained that the group responsible for this draft consists mostly of those whose psychiatric bias is well known: as a result the Guidelines on ME/CFS are extremely biased, and in many respects demonstrably misleading and erroneous. The group is led by Peter White, Professor of Psychological Medicine at St Bartholomew’s and The London Queen Mary School of Medicine and Dentistry; other members include Professor Tom Sensky from the Department of Psychological Medicine, Imperial College, London (representing the DLAAB); Dr William Bruce-Jones, Consultant and Liaison Psychiatrist, Avon & Wiltshire Partnership Trust; Dr AK Clarke, Medical Director, Royal National Hospital for Rheumatic Diseases, Bath (with a physiotherapist and an occupational therapist from his unit), but no immunologist, neurologist or vascular medicine specialist with published expertise in ME/CFS.

In addition to the usual biopsychosocial construct of ME/CFS, the draft Guidelines contained many false statements, for example:

- “In the past the term neurasthenia was used to describe the condition” (this is untrue; the term was epidemic neuromyasthenia)
- “Most authorities consider the condition as CFS/ME” (they do not: this was deliberate social constructionism by those favouring a psychosocial model of ME/CFS, about which Wessely is on record: **“It may seem that adopting the lay label (of ME) reinforces the perceived disability. A compromise strategy is ‘constructive labelling’: it would mean treating chronic fatigue syndrome as a legitimate illness while gradually expanding understanding of the condition to incorporate the psychological and social dimensions. The recent adoption by the UK Medical Research Council and the chief medical officer’s report of the term CFS/ME reflects such a compromise”** --- BMJ 2003;326:595-597. Wessely’s influence at the MRC, where he was a member of three Boards, and on the CMO’s Working Group, is a matter of record)

- “There is no evidence that persisting infection is responsible for the continuation of fatigue and associated symptoms” (there is significant published evidence of persisting infection)
- “In recent years steps have been taken by experts to formulate criteria” (the Oxford 1991 criteria and the CDC 1994 criteria have come under repeated fire because they expressly include those with psychiatric disorders)
- “The symptom of fatigue...” (no-one except Wessely School psychiatrists is talking about “fatigue” in relation to authentic ME/CFS but about overwhelming, incapacitating post-exertional exhaustion and malaise)
- “There are no confirmatory abnormal findings on physical examination” (this is untrue)
- “There (is) no abnormal blood test...” (whilst it is true that there is no single, definitive blood test, there is a specific constellation of reproducible laboratory tests that are virtually diagnostic)
- “...beliefs that exercise is damaging” (a compulsory exercise regime may well be damaging in an unquantifiable number of patients, not only because of impaired cardiac and respiratory function as well as damaged mitochondria, but because it induces oxidative stress which may induce more severe illness; in addition, there is poor elasticity of vessels, with arterial stiffness and insufficiency)
- “Some people who rest a lot may have postural hypotension” (the inference here is unmistakable, but postural hypotension is not the same as orthostatic hypotension that is found in ME/CFS: postural hypotension is an immediate fall in blood pressure greater than 20 mmHg when moving from supine to vertical often seen in the elderly; orthostatic hypotension is an abnormal change in the heart rate and blood pressure over time; postural orthostatic tachycardia syndrome (POTS), as occurs in ME/CFS, is an increase in heart rate of 30 bpm or more when moving from supine to vertical within ten minutes; chronic orthostatic intolerance – as occurs in ME/CFS -- includes symptoms such as dizziness in all patients, altered vision, nausea, neurocognitive defects, disordered thermoregulation, palpitations, tremulousness, headache, difficulty breathing, sweating and pallor)

- “An explanation that the illness is not progressive or life threatening is an important initial step” (it is untrue that ME/CFS is not progressive: it may be, and certainly can be fatal, not only through suicide)
- “People are encouraged to view symptoms as reversible” (although symptoms fluctuate – which is a cardinal feature of ME/CFS – they are not usually reversible, especially in the chronically and severely affected)
- “Addressing fears and re-interpreting disabling symptoms allows the person to make a gradual improvement” (recognition of the physical nature of the disabling symptoms shows that the person has insight)
- “Antidepressants may be very helpful, eg. fluoxetine...” (many people with ME/CFS suffer adverse reactions to drugs, even at reduced doses, and there is compelling published evidence that fluoxetine should never be used in ME/CFS)
- “The term CFS/ME describes a spectrum of disorders” (the term ‘CFS’ has indeed become a heterogeneous one entirely due to the highjacking of it by the Wessely School psychiatrists to mean what they want it to mean, in defiance of the WHO official terminology whereby ME/CFS is a nosological entity, ie. a specific disorder. This is why the international ME/CFS research community -- excluding adherents to the Wessely School -- is calling for urgent sub-typing of ‘CFS’ because the present situation is unscientific and hampers competent research due to the invalid comparison of contradictory research findings)
- “Clinical examination: specifically there are no abnormal signs found in the neurological or musculoskeletal systems” (this is untrue: there are definite abnormalities in these systems, for example, an abnormal Romberg test; nystagmus; altered tandem gait; ataxia; neuromuscular incoordination; typical cogwheel movement of both legs, coarse tremor of hands when arms are held outstretched, discolouration of the skin with autonomic circulatory changes indicating abnormal vaso-receptor control etc)
- “Neuromuscular function is normal” (this is untrue)
- “Impairment of cognitive function (is) usually only mild” (this is untrue)

- “Most people who attend hospital for treatment will make a significant improvement with appropriate treatment” (this is untrue and there is no such evidence in cases of authentic ME/CFS)
- “Profound fatigue would not normally render the person completely unable to walk” (it may well do so, due to the metabolic abnormalities mentioned above)
- “No abnormalities of balance....balance is likely to be normal” (this is untrue)
- “This level of chronic fatigue syndrome causes no significant cardio-respiratory, musculo-skeletal or neurological impairment” (this is untrue)
- “Manual dexterity is normal” (this is untrue)
- “Hearing, speech and vision are normal” (this is untrue).

(The evidence that the draft Guidelines are erroneous in these respects is contained in our Submission dated 12th December 2005 to the Gibson Inquiry).

On 13th July 2005 the Medical Adviser to the UK ME Association, Dr Charles Shepherd, wrote to Dr Roger Thomas, DWP Corporate Medical Group, Room 623, The Adelphi, 1-11 John Adam Street, London WC2N 6HT in the following terms:

“Unfortunately, we were very disappointed with the response to our criticisms of the current draft, in that the response clearly implies that the DWP is happy with the overall content and the way in which (it) is likely to affect the decision making process for future benefit applications from people with ME/CFS.

“The ME Association remains convinced that the overall content will only make a bad situation even worse, and that this document requires a complete re-write by a more balanced group of health professionals”.

In his letter, Dr Shepherd addressed key areas of concern:

(1) the biased composition of the group that prepared the draft; (2) some of the statements in the draft indicate that the group has no practical experience of understanding the illness they purport to describe; (3) the guidance is very muddled; (4) information on causation is strongly biased toward the psychological model and contains speculation and opinion presented as fact; (5) information on symptoms is strongly biased towards the psychosomatic model; (6) the information on management is over-simplistic and strongly biased towards the psychosomatic model, and (7) the draft failed to acknowledge points contained in the Chief Medical Officer's Report (of January 2002) which are relevant to benefit provision.

On 14th October 2005 Dr Shepherd posted a notice on Co-Cure in which he said: "The ME Association made it clear to the DWP that the draft we received at the end of the meeting in June was completely unacceptable. The revised draft appears to have been written by the same group of health professionals. Some parts are still far too biased towards the psychosocial model of causation and treatment. The guidance provides a very inadequate, and in places, inaccurate, picture of the disability caused by, and the needs associated with, moderate to severe ME/CFS. This will probably be the last opportunity for several years for charities representing people with ME/CFS to obtain medical guidance for benefit purposes that will help to reverse the current scandalous situation whereby far too many genuine claimants are being refused DLA".

At a meeting at the DWP held on 17th October 2005, "revised" draft Guidelines were considered. Whilst some semantic amendments to the previous version had taken place, many of the inaccuracies from the previous version remained and the overall message was the same: "CFS/ME" is to be considered a psychosocial disorder that is heavily dependent on the aberrant "beliefs" of sufferers.

The meeting was robust, and those representing people with ME/CFS continually emphasised that any new guidance must be accurate and must contain a better description of the level of disability faced by those with moderate to severe ME/CFS. The ME Association had made it clear that a new group of health professionals should be appointed to produce guidelines that were based on the scientific evidence, but the DWP resolutely refused to agree to this.

A further draft is awaited in the New Year, but when the Guidance is finally published it will be in electronic form, unlike the current (paper) Handbook.

Commenting on the present situation, Simon Lawrence, Chair of the 25% Severe ME Group, wrote as follows: “The document contains an inadequate description of the disease, exhibits a distinct lack of current knowledge, proposes no investigative procedures where routine screening has failed, promotes opinions not supported by research and for which no proof exists, and postulates two unproven psychological interventions where claims made for their efficacy are not supported by research findings both in the UK and abroad, and are at variance with patients’ reports. Of particular concern is the way in which this very complex disease, which affects every system in the body, is reduced to fatigue, and takes no account of neurological, immunological or endocrinological factors. It leads the reader to believe that ME/CFS is a psychological disorder; no proof for this view exists” (The Quarterly, Issue 20; Winter 2005, page 5).

Comparison of the UK DWP approach with the approach set out in a Report commissioned by the New Zealand Ministry of Health

In 2003, a comprehensive analysis of four international Chronic Fatigue Syndrome Guidelines was prepared for the New Zealand Ministry of Health at its request; it was prepared by reviewers with good understanding of evidence-based healthcare, all of whom were familiar with a standardised review instrument (Appraisal of Guidelines for Research & Evaluation: The AGREE Collaboration) and all of whom had an awareness of ME/CFS.

Specifically, the reviewers were asked to comment on the methodology by which the Guidelines were produced, on the content of each of the Guidelines, and whether the reports contained any apparent bias.

The four Guidelines reviewed were:

1. The Royal Australasian College of Physicians report “Chronic Fatigue Syndrome: Clinical practice guidelines”; 2002 (although the document had been some years in development)
2. A Report of the UK CFS/ME Working Group: “Report to the Chief Medical Officer of an Independent Working Group”; 2002

3. US Guidelines produced by the Academy of Medicine, University of Medicine and Dentistry and Department of Health Services, New Jersey: "A Consensus Manual for Primary Care and Management of Chronic Fatigue Syndrome"; 2002
4. Canadian Guidelines: "Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols", produced by Health Canada Expert Medical Consensus Panel; 2003.

Extracts from the Report commissioned by the New Zealand Ministry of Health are produced here for comparison with the view of the UK DWP.

"On 12th May 2002 (ME Awareness Day), Acting Social Services and Employment Minister Ruth Dyson made the announcement that the Government had accepted Myalgic Encephalomyelitis, or Chronic Fatigue Syndrome, as a physical illness".

New Zealand Reviewers' Comments on the Australasian Report

(note that this Australasian Report is the one upon which the UK Medical Research Council relied so heavily in its CFS/ME Research Advisory Group "CFS/ME Research Strategy" Report of 1st May 2003)

"The reviewers felt that this Guideline had too strong a psychological approach"

"Possibly resulting from the psychiatric bias, it was felt that this Guideline showed a bias towards the now outdated management practices of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET)"

"The reviewers commented that the research about CBT is ambiguous and inconsistent, and that GET may cause relapses and is therefore potentially harmful"

"The severely ill were not included"

“Patients’ views were sought, but the finished Guideline does not reflect them”

“The considerable dissent at the public consultation meeting was not reflected in the Guideline”

“There was no discussion of outcomes”

“There was not enough attention to harms and risks”

“The Report was too ‘certain’, given the acknowledged conflict in the evidence base”

“There were no statements of potentially conflicting interests”.

New Zealand Reviewers’ Comments on the UK CMO’s Report

“The reviewers commented that a particular shortcoming of the CMO’s report is the Anglocentric nature of the research base and the consequent omission of relevant research evidence from international studies”

“It was also felt that there was over-representation from psychiatry on the team, leading to too strong an emphasis on psychological issues”

“The report as a whole was overshadowed by extreme professional positions”

“The report still recommends CBT and GET, albeit acknowledging the paucity of research support for these approaches”

“The potential for harm from GET is not adequately discussed, nor is the controversy surrounding CBT”

“Particular categories of patients should have had particular attention”

“Neurology was not well represented on the team”

“Dissent, and team membership changes and resignations, raised questions about consensus”

“There was limited scope of the literature reviewed (it overlooks much non-UK literature)”

“There was glossing over of some potential harms -- eg. of medications”

“The report makes recommendations which may be harmful (eg. GET)”

“The report is really a summary of ‘expert opinion’ (that has been informed) by selective evidence”

“The report needs the incorporation of international research”.

New Zealand Reviewers’ Comments on the New Jersey (US) Guidelines

“This Guideline was liked particularly for its broad coverage, particular attention to discrete aspects of the condition, and compassionate approach of the specialist authors”

“The section on ‘behavioural management’ was more acceptable (as) the adverse effects of therapies was felt to be well covered”

“The report had a good evidence base with a comprehensive scope of international research”.

New Zealand Reviewers’ Comments on the Canadian Guidelines

“Of all the Guidelines reviewed, this was the one (about) which the reviewers were most enthusiastic”

“The reviewers found the Canadian Guideline to be written with compassion and understanding for people with (ME)CFS”

“They also felt it adopted a more balanced model of (ME)CFS and that it had useful management suggestions which reflect both benefits and risks of various treatments for people with (ME)CFS”

“The Canadian Guideline has academic rigour (including peer reviewing)”

“It was comprehensive and (had an) up-to-date evidence base (and was) well-referenced”

“It had clear differential diagnostics and definitions between various fatigue states”

“There was excellent consideration of risks as well as benefits”

“It was excellent at specialist level”.

New Zealand Reviewers’ Specific Comments on the Risks of CBT and GET

“GET as applied to ME/CFS patients is (potentially) harmful. Continually increasing exercise may eventually cause a relapse and patients want to avoid this at all costs. Diagnostic criteria for ME/CFS have as their focal point ‘fatigue and malaise made worse by exercise’. In countries where Guidelines recommend GET, there have been cases where children have been removed

from their parents because of it. This occurs when children or their parents on behalf of them have refused this treatment. The Guidelines are then cited as proof of a worthwhile treatment which is being refused. Such a situation would be a disaster if it were to occur in New Zealand”

“The specific situation with GET occurred because the Guidelines recommending GET had been based on out-of-date evidence reviews”

“(New Zealand must) avoid the risks of making recommendations shown by more recent research than that included in the evidence base to be ineffective or even harmful, as has been the case with some of the reviewed Guidelines”

“Evidence is not always clear-cut and there may be uncertainty about the best management. In this case the uncertainty should be stated in the Guideline”

“There are circumstances where members of the development group may have conflicts of interests. For example, this would apply to a member of the development group whose research on the topic covered by the Guideline is also funded by a pharmaceutical company”

“There should be an explicit statement that all group members have declared whether they have any conflict of interest”.

The Gibson Inquiry members will not fail to note the striking differences between the approach of the UK DWP and the approach set out in the Report commissioned by the New Zealand Ministry of Health towards patients suffering from the same disorder, especially the legitimate concerns about the Wessely School CBT / GET regime – and the inherent dangers of that regime -- that is to be compulsorily imposed in the UK upon ME/CFS patients who claim State or insurance benefits.

CONCLUSION

The Government’s goal of reforming the State benefits system is well-known: the intention to force cognitive behavioural therapy on those seeking sick notes was highlighted in an article on Sunday 20th November 2005 in The Observer, (“Therapy for those seeking sicknotes”) in which Gaby Hinsliff, the political editor, wrote:

“Margaret Hodge, the Welfare Minister, wants to use so-called cognitive behaviour therapy – a fashionable ‘talking cure’ used to change habits – to encourage people to return to work. (This) would be part of a ‘carrot and stick’ approach, under which people judged capable of working could have their benefits docked unless they take steps towards employment. Hodge said it was ‘not unreasonable’ to require something in return for benefits”.

This message was replayed by John Hutton, Secretary of State for Work and Pensions on 27th December 2005, as reported in the Independent by Andrew Grice (“Sick and disabled targeted in benefit reforms”): “Most sick and disabled people will have to seek work to receive maximum state benefits under welfare reforms to be announced next month. John Hutton has disclosed that the 2.7 million people on incapacity benefit will have to earn the right to it by taking advantage of “rehabilitation”. Ministers will insist that the ‘carrot and stick’ approach is in line with Labour’s traditional values. The tougher regime will apply only to new claimants. But Ministers hope to transfer existing claimants to the new rules over time”.

With regard to DLA, Steve Donnison of Benefits and Work has obtained documents which show that a new points style system is being piloted for this benefit. The new computerised system will prevent people with a range of health conditions from receiving awards of the care component, the mobility component, or both. The software even stops decision-makers giving DLA care payments to war veterans. Decision-makers are warned not to trust any information given by such people.

The new software is currently being piloted in Bootle and Manchester; if the DWP is happy with it, the software is likely to be rolled out nationally in 2006 and will be used not only on all fresh claims for DLA but also on renewal claims.

The five hundred and fifty pages covering over 60 different disorders include information about who the decision-maker should collect evidence from; it also contains a warning to decision-makers that people with ME/CFS who use a wheelchair can still walk 100-200 metres and are thus not eligible for higher rate mobility allowance.

The section on “CFS” is 33 pages long.

A copy of the biopsychosocial model training materials for doctors can be obtained free from the DWP (freedom-of-information-request@dwp.gsi.gov.uk).

Benefits and Work has enough information to understand how, using the answers to a very brief series of multiple choice questions, the computer decides what award of DLA the claimant will receive, and for how long, and then produces what appears to be a very detailed and carefully reasoned decision letter.

These proposed changes have caused deep concern within the ME community.

It is beyond doubt that the unproven therapies of the Wessely School, based on flawed research, will be forced on those with ME/CFS in defiance of the scientific evidence that these “rehabilitation” regimes could cause serious and lasting harm to such patients.

The Wessely School psychiatrists cannot innocently claim that they are referring to “medically unexplained chronic fatigue” and not to ME/CFS: this would be untenable because their work contains many explicit references to ME/CFS as a psychosocial behavioural disorder.

As Simon Lawrence pointed out on 27th September 2005 on Co-Cure:

“With the amount of biomedical research now available showing significant and substantial physiological abnormalities in ME/CFS patients, it is no longer acceptable for unsubstantiated opinion and theories about personalities of ME/CFS patients to influence public policy. The psychiatric profession has been at the forefront of the attempt to portray ME/CFS as a psychosomatic disorder with no physiological basis. This view has been invalidated by medical science and it is not appropriate for psychiatrists to pronounce on the illness further. We will ensure that any attempt to influence DWP decision-makers to use a psychosocial model for ME/CFS will be met with resolute opposition”.

The issues raised in this document concerning the undisclosed commercial conflicts of interest on the part of those seeking to impose their own “rehabilitation” regimes upon the sick and disabled in the UK ought to be of immediate concern to the BMA Ethics Committee and to the Professional Conduct Committee of the General Medical Council.

In view of the failure of all previous Working Groups to take on board the empirical scientific evidence about ME/CFS, it is hoped that the outcome of the Gibson Parliamentary Inquiry will produce the long-awaited breakthrough so that the additional burden of unnecessary financial hardship forced upon those with ME/CFS -- many of whom are very sick -- may finally be alleviated.